

Testimony of Kathleen Burke
Senate Special Committee on Aging Hearing
Alzheimer's disease: A Big Sky Approach to a National Challenge
South Park Senior center, Billings, MT
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Senator Walsh, individuals who recommended my participation, fellow panelists, and audience members, thank you for participation in this vital hearing. It was with a humbling sense of responsibility that I accepted the invitation to testify and bring a common face to Alzheimer's. According to the 2014 Alzheimer's disease Facts and Figures report by the Alzheimer's Association, most of the general difficulties that I will present are experienced by many Alzheimer's families, with slight variations. I apologize ahead of time for speed reading a subset of my submitted testimony, but I am concerned about the time don't want to miss points, especially educational ones.

My name is Kathleen Burke and unfortunately I have a family history of Alzheimer's and related brain disorders on both sides of my family for at least two generations, including grandparents, both parents, aunts, and uncles. I helped my maternal grandparents in the 1970s when I was the only relative within 900 miles. I resumed caregiving when my mother Shirley was diagnosed with Alzheimer's in 2002 and my father Jack in 2010. My almost 92 year old mother, entered a nursing home in January 2013 initially for rehabilitation from mild strokes, but stayed permanently due to her Alzheimer's, which is now in the end stages. My father, who was on medication for his mild symptoms of Alzheimer's, died last September of pancreatic cancer at the age of 88.

I am honored to speak on behalf of the estimated 48,000 caregivers for the 18,000 Montanans currently diagnosed with Alzheimer's disease. Partially due to Montanans' longer life expectancy, the number of Alzheimer's patients is projected to increase in Montana by 50% by 2025. This is a startling forecast that we need to derail. When the government provides to Alzheimer's disease the level of financial support that has been given to cancer and heart disease research for the last 40 years, tremendous strides should also be accomplished for Alzheimer's.

The Alzheimer's Association provides this list of ten warning signs to assist in deciding if one should seek medical consultation regarding actions exhibited by individuals. The signs are memory loss that disrupts daily life; challenges in planning or solving problems; difficulty completing familiar tasks at home, at work, or at leisure; confusion with time or place; trouble understanding visual images and spatial relationships; new problems with words in speaking or writing; misplacing things and losing the ability to retrace steps; decreased or poor judgment; withdrawal from work or social activities; and changes in mood and personality. According to their 2014 Alzheimer's Disease Facts and Figures report, the personal difficulties that I will present are experienced by many Alzheimer's families, with slight variations.

I was excited and relieved when my parents began receiving Veterans Administration (VA) funded care through the Yellowstone County Program of All-inclusive Care for the Elderly (PACE) thinking that their health care needs were finally arranged for life. Unfortunately Montana decided to be the only state to withdraw its participation after providing partner funding for only two years. Since PACE closed in 2011 the money that VA was providing for my parents participation was not available for other VA programs. I have arranged care using the VA, Medicare, private supplemental medical insurance, medical personnel, day care, in-home care, family, and other sources. I worked to arrange the first day care Provider Agreement for VA in Montana, but it failed. We have experienced waits of up to a year for

determination of eligibility for benefits. I have more forms to submit for benefits, but it is depressing just thinking about the process. My father's 100 % service-connected disability benefits included free dental, free drugs, and VA contracted nursing home, but not my mother, who is actually in more need now, does not get these benefits,. Dad died the day before he would have taken advantage of the free nursing home benefit. The VA does not work well with Medicare, so it would really help our family if benefits could be applied to either family member when both are veterans and one did not get to receive these benefits.

Personality changes are common and can cause rifts in families if one does not remember that the disease adversely affects the person we used to know and relationships with them. When my father was yelling at me, I got very close to his face because he was hard of hearing and asked him loudly, "Do you know how hard it is to help you as much as I do when you yell at me like this?" He responded, "That's just the way I am and I'm too old to change."

Memory loss is a classic symptom. Mom put an appointment on the calendar, but didn't know why. I took off work and met the cemetery salesman. He was discussing plots in a veteran's section of a local cemetery, so my parents thought it was free for vets. I was relieved recognized the salesman, mentioned Mom's Alzheimer's, and explained they would not be buying.

Another sales person sold Mom a medical insurance policy that she thought was part of Dad's employer's coverage, which it wasn't. My parents had unneeded double insurance with five years of payments, which neither of them understood until I discovered it while trying to fix their checkbook.

One of the typical warning signs was when my parent's check book was mismanaged by Mom, who took care of the family finances. Thinking it was advertising, Dad would discard mail without opening it. Mom had accepted a free Reader's Digest Condensed book. If you did not tell them to stop, they kept sending them for a charge. I found a \$52 bill that started out at \$19 and all the rest was interest charged when she forgot to pay and Dad didn't realize it was overdue. I explained the dementia situation and paid the original bill.

Another typical warning sign was when Mom couldn't complete familiar tasks, such as cooking. Mom was baking a frozen pizza for supper, with the plastic wrap still on it. I came into the house to the smell of smoke. She said she always did it that way. Needless to say, it was no longer safe for her to cook and Dad didn't know how, so that required additional food preparation problem solving on my part.

Confabulation can be exhibited by Alzheimer's patients as misinterpreted memories. My mother told the nurse that her sister had committed suicide, when it was actually the daughter of her bridge partner.

Anger and anxiety are experienced by many Alzheimer's patients. Once at work I had to interrupt a class to deliver a message to a student about his family in Great Falls. His Alzheimer's afflicted father had beaten his mother so severely that she was taken to the hospital and his father was arrested.

Loss of problem solving skills and poor judgment are exhibited in different ways. Mom was scheduled to have thumb surgery for arthritis, but she decided to cancel it because she was dominantly right-handed. For several weeks before the surgery we practiced using her left hand for eating, tooth brushing, toileting, and other personal needs. It took much patience and practice, but she finally had the surgery, which greatly reduced her arthritic hand pain.

Mom was dropped off at a casino to play cards, but Dad remembered the wrong day so no players were there. Rather than thinking to phone family members, she accepted a ride from a stranger to take her home. I was shocked because this could have turned out very poorly had he taken advantage of her.

Dad drove Mom to the Senior Center for cards. He was confused, thought I was going to bring her home after work, and phoned when we did not show up by 5:30 PM. When I got to the center, which closed at 5 pm, she was sitting outside waiting for pickup.

My parents' medical insurance premiums were supposed to be paid for life by Dad's large retail employer, but they have had to pay them for approximately 10 years. A promised \$100,000 life insurance policy was cut several years ago to \$8,500. I realized after his death that he was offered some type of life insurance that he could have purchased through the employer at a reduced rate, but he was so angry he refused it without discussing it with his family.

Many Activities of Daily Living (ADLs) need to be assisted by caregivers. I would call Mom daily to ask if she had taken the pills set up for her and if she was dressed. I started to find chewed gelatin pills in the garbage and on the floor. One day she had two shoes of different colors, whereas another time she had on two right loafers. One night when I saw her limping and asked why, she didn't know. I took off her shoe and found a sock crammed in the toe of the shoe. Dad hadn't noticed when he had put on her loafers that day. He was angry when I suggested he had to pay more attention when helping before day care. His typical response was, "You don't understand."

When my Dad had a brain abscess in 2007, I had to take Mom to work with me because I could not safely leave her by herself. It was difficult to find senior day care in Billings then, it is still limited, and may require a contract as opposed to meeting drop-in needs. The client has to be quite independent to participate. As her disease progressed, I was given a week to make toileting arrangements or she could no longer go there. I found a certified agency who had a person that the VA paid to help her for 30 minutes each day Monday through Friday.

It is theorized that social isolation and lack of physical and mental exercise might be risk factors for Alzheimer's. Mom did not drive, so she was always dependent on others for transportation. Since diagnosis most of her day was spent being a meticulous homemaker, knitting afghans, and playing solitaire. Outings were to buy groceries, go to church, play cards, and to eat out. She really looked forward to playing cards about four times a month with various groups. Over several months all phoned me to say she couldn't play with them anymore because of forgetting to pay her dues or for food ordered or inappropriately announcing what cards she had when they were good. As a family we would try to do some daily brain activities, such as card games, Wheel of Fortune, or the monthly Readers Digest vocabulary test. Dad would also do search-a-word puzzles. Mom could not do the special 60th Anniversary search-a-word I made for them in 2005, saying the letters were too small for her to read. She didn't realize her mental contribution to difficulties.

It is common to exhibit increased confusion in unfamiliar surroundings. During an Emergency Room (ER) trip, I explained to the doctor who I was and about Mom's dementia, but he did not want me to answer questions for her. He asked Mom who I was. She looked at me, hesitated, and said, "She is a very good friend." She gave no name. At that point the physician accepted my answers. On another occasion I had to move my car when Mom was in the hospital. She was very confused, so I stopped at the nurses' station to remind them to watch her while I was gone so that she did not remove the IV or pull off the chest leads for the 24 hour 12 lead ECG. When I returned after less than 10 minutes, no one was with

her and she was bleeding from where she had pulled out the IV and had several of the leads removed. On December 23 I had to stay in the chair next to her bed all night to prevent her from interfering with overnight testing when the hospital was unable to provide the care they promised. I went directly from the hospital to my regular eight hour job. When Mom moved into the nursing home, I was concerned with her walking in unfamiliar surroundings. I was not happy that the bed had no safety railings, but rather a low level plus a pad on the floor on which to land if she fell out of bed. The second night the wheels on the bed were not locked, she fell out of bed onto the hard floor between the bed and the wall where there was no pad, suffering a cut on her arm. She could not get up and staff did not find her for approximately two hours. Mom's increased confusion in unfamiliar surroundings, coupled with lack of Alzheimer's knowledge on the part of physicians and nurses, made for miscommunication and injury. These instances point out that Alzheimer's education is needed for everyone, including medical personnel, to meet the needs of these patients. Employers are another group for which education would improve understanding as to why employees need to be gone from work for caregiving for family members with Alzheimer's.

Several years ago when I came into the house, mom was not sitting in her chair next to my dad. He said, "We lost your mother." I was shocked, thinking she had died. He then continued, "I never thought this could happen to such a smart person. The sparkle is out of her eyes. She'll never again be the same."

Even after physical therapy instruction Mom could not get up by herself after she had fallen and Dad could not get her up by himself, so he would have to call my brother or me to come help. Dad was afraid to go outside to water the flowers for fear Mom would fall inside and he would not hear her.

My brother was fearful that my dad's wanting to save money by keeping mom out of a nursing would take a toll on Dad's failing health, which happens to caregivers. When I was forgetting things at work, I underwent testing and was told my memory problems were related to work and caregiver stress. I now have baseline data that can be referred to in the future.

I have utilized the redirect technique for both parents. I explained to Dad how important it was to have two people at medical appointments, but he looked on it as an infringement on his independence and privacy. He would stand in the parking lot, or worse, in the reception area in the doctor's office and yell at me, saying I did not need to be there. I knew his social filter was affected by his disease, but I still found this quite embarrassing. I believe a sense of humor helps cope with this disease, so our family teases a lot. I told him that since he was so hard of hearing and didn't understand medical terminology I would serve as his personal secretary. With his retail management background, he was used to having people do things for him, so he could relate to this. Finally, although reluctantly, he allowed me to help and would actually introduce me as his personal secretary.

Driving is a huge issue for Alzheimer's victims and their families. After 12 years of discussion in caregiver meetings, I can remember only three people who gave up driving on their own, which was not the case for my dad. This problem warrants a separate discussion at a different time.

At the end of their 68th anniversary celebration in the nursing home on July 4, 2013, Mom pushed Dad away when he bent over to kiss her good bye, saying that her husband would not like that. It was difficult for me to see, but probably worse for him since he would not talk about it. He was diagnosed with pancreatic cancer in August and didn't visit her after that. Knowing that she would not understand, it still hurt not to tell her that her husband died of pancreatic cancer or that his funeral was one day

before her 91st birthday. This was a stressful time for all family members, who had to change from being sad to happy in a 24 hour period to celebrate her birthday.

I considered retiring early so I could take care of Mom, but realized it was a 24/7 job for which I did not have enough support. I still feel guilt, even though I know it was a logical decision. I visit her daily, but she usually does not realize who I am. Her disease doesn't allow her to speak many words, she is confined to a wheelchair, and her hands are contracting. I miss both of my parents; one who died physically and one who has died mentally.

My faith has helped me cope with this disease. I think God has a sense of humor, realizes that patience is not one of my better virtues, and has provided multitudinous Alzheimer's opportunities for me to work on that virtue.

In closing, thank you for allowing me to testify. With proper funding, I am looking forward to what can be done for Alzheimer's to prevent the terrible Montana forecast from becoming a reality.